



NATIONAL CENTERS OF
EXCELLENCE
IN WOMEN'S HEALTH

Chronic Illness and Disability

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OFFICE ON WOMEN'S HEALTH
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AND HUMAN SERVICES

The National Centers of Excellence in Women's Health (CoEs) were established by the Office on Women's Health, within the Department of Health and Human Services in 1996. Their mandate is to establish and evaluate a new model health care system that unites women's health research, medical training, clinical care, public health education, community outreach, and the promotion of women in academic medicine around a common mission—to improve the health status of diverse women across the life span.

Today, twenty-six million American women are living with disabilities, varying conditions that make their roles even more challenging because of physical or mental limitations. Various diseases and conditions produce some form of disability, and a number of them disproportionately affect women. In general, the severity of a disability is described in terms of how much that disability limits one's daily activities. Women are more likely than men to be limited in the amount or kind of major activity they can perform. However, disability rates for both sexes increase as age increases. Depending on the source, the word disability is defined in different ways. For this brochure, we use the Department of Justice definition of physical disability:

- Any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine; or

- Any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.

Chronic illnesses such as heart disease, diabetes, and osteoporosis also adversely impact women. Such illness persists for a long period of time—3 months or more as defined by the U.S. National Center for Health Statistics. Barriers faced by women with chronic illnesses and/or disabilities include:

- Physical barriers, such as architectural barriers and lack of adequate transportation and support services to keep appointments, run errands, or receive medical care;
- Financial restraints; and
- Lack of reliable health information and services that address their needs.

This brochure highlights activities and programs at the CoEs that address specific health resources and care provided for women suffering from chronic illnesses and/or physical disabilities.

Clinical Care

◆ Harvard University CoE

The Gillette Centers for Women's Cancers are located at two sites within the CoE: the Dana Farber Cancer Institute/Brigham and Women's Hospital (BWH) and Massachusetts General Hospital (MGH). The Gillette Centers were opened in November 1997 to provide multidisciplinary care to breast and gynecological cancer patients. The Gillette Centers offer an array of comprehensive clinical services to meet patients' needs, including: diagnosis of breast or gynecologic cancers, evaluation and treatment of breast

or gynecologic conditions associated with previous cancer treatments or other cancers, development of individualized treatment plans with the latest treatments (surgery, radiation, chemotherapy), long-term care, genetic counseling, individual/family counseling, rehabilitation/physical therapy, nutrition counseling, palliative care/pain management, and support groups. In addition, the Gillette Centers offer breast and cervical cancer screening and education programs in underserved communities. Working committees, consisting of physicians from numerous specialties from all participating institutions, also conduct a series of clinical studies in cancer treatments. The Gillette Centers include:

- The Beth Israel Deaconess Medical Center's Breast Care Center provides services for women diagnosed with breast cancer. These services include: surgery and breast reconstruction, radiology, radiation therapy, pathology, oncology, and counseling and support groups. Women have the opportunity to obtain an evaluation or second opinion from breast specialists from medical and radiation oncology as well as surgery. The Center treats breast cancer with lumpectomies and radiation therapy instead of mastectomies.
- The BWH Comprehensive Breast Center serves women who have breast conditions that require further evaluation. At the Center, abnormal mammograms, breast lumps, nipple discharge, and other problems are evaluated. Some of the services provided include: physical examination, state of the art diagnostic procedures (e.g., fine needle aspiration biopsy, stereotactic core needle biopsy, and ultrasound guided core needle biopsy), and MRIs.
- The breast health care services offered at the Massachusetts General Hospital's Comprehensive Breast Health Center

integrate expertise of radiation and medical oncologists, breast surgeons and specialists in radiology, pathology, nursing, social work, and rehabilitation medicine. The Center's goals are to provide sensitive patient care while using the most sophisticated medical technology available today. Providers see patients with general breast problems or concerns as well as those who have already been diagnosed with breast cancer. The Center offers comprehensive breast care services ranging from routine examinations to complex breast surgery and cancer management. The radiology department offers mammography and interpretation services. The Center provides a comprehensive team approach to the evaluation and treatment of breast disorders. Prevention and early detection are the hallmark of its approach to breast care.

The CoE hospitals offer women-centered cardiology care that links the latest and most relevant clinical information and research regarding women and cardiovascular disease to the care of women patients. Services are designed to address the unique cardiac health needs of women in a female-friendly environment. Strong emphasis is placed on prevention and total cardiac health and is recommended for women with heart disease as well as healthy women concerned about their cardiac risks. Services include:

- Comprehensive evaluation and treatment of cardiac risk factors, such as high blood pressure, high cholesterol, smoking, excess weight, and stress;
- Expertise in analyzing the benefits and risks of hormone replacement therapy in perimenopausal and postmenopausal women;
- Evaluation and management of chest pain and coronary artery disease;

- Interdisciplinary approaches incorporating exercise, stress management, relaxation response, nutrition, and other risk-reduction programs;
- The most advanced information and treatments available for heart disease, heart failure, and arrhythmias, provided by board-certified cardiovascular specialists; and
- Evaluation and management of heart disease in pregnant women.

The Women's Program at the Joslin Diabetes Center offers gynecological services to women of all ages with diabetes. The staff are diabetic specialists in gynecology and endocrinology. The program offers complete gynecological care, osteoporosis evaluation and treatment, menopause evaluation and hormone replacement, evaluation of irregular or absent menstrual bleeding as well as heavy or prolonged bleeding evaluation and treatment of pelvic pain and pregnancy planning.

The multidisciplinary Beth Israel Deaconess Medical Center's (BIDMC, a CoE affiliate) Women's Health and Epilepsy Program approaches the diagnosis and treatment of women with epilepsy via a team approach, involving the patient, her epilepsy physician, an epilepsy nurse, the patient's internist and/or obstetrician-gynecologist, and other members of the program, including social workers, neurocognitive specialists, and resource workers. For women who are considering pregnancy, a customized pregnancy checklist and labor and delivery plan is used to help facilitate communication between members of the treatment team. Patients are seen monthly by their epilepsy physician and nurse to monitor the need for additional medication and to improve health promoting behaviors such as adequate sleep and nutrition in order to decrease the likelihood of seizures during pregnancy.

For women who deliver at BIDMC, an inpatient postpartum visit is made by the epilepsy physician to examine both the mother and the new baby. An additional focus is placed upon possible changes in the pattern or frequency of seizures for women approaching menopause. An active research program is maintained, and is open to all patients followed in the program.

The CoE's hospitals utilize an interdisciplinary approach to the treatment of women with urological problems. These hospitals offer pelvic reconstructive surgery and lower urinary tract dysfunction treatment, including, but not limited to, urinary incontinence, urgency, and frequency. The program provides a comprehensive evaluation for a broad array of voiding dysfunctions. Many treatment options are available, including behavioral, pharmaceutical, and surgical interventions. Evaluation of urinary incontinence includes urodynamic studies, history and physical exam, behavioral treatment modalities, pharmacological interventions and continence surgery.

The Center for Women's Health of the BIDMC Mind/Body Institute is dedicated to clinical and basic research in the application of mind/body medicine to women's health. Mind/body therapies are only now being studied in a scientifically rigorous fashion, and the preliminary data are significant. Recent clinical studies on the application of mind/body medicine to women's health have shown significant therapeutic benefit in a non-invasive, cost-effective fashion for infertility, menopause, and breast cancer. This outpatient medical clinic applies the principles of behavioral medicine to the treatment of chronic illness and symptoms of medical disorders in women. The Center collaborates with the divisions of gynecologic oncology at the BIDMC, BWH, Dana Farber Cancer Institute, and MGH and with reproductive endocrinology at BWH and Boston IVF.

Through a multidisciplinary team approach, the biopsychosocial model of health is applied to all aspects of health care.

◆ **Wake Forest University CoE**

Wake Forest University CoE's Geriatric Outpatient Clinic located in its Sticht Center on Rehabilitation and Aging was built and includes exam rooms specifically designed to accommodate older adults and persons with disabilities.

The Breast Care Clinic, a CoE affiliate, provides a seamless system for women who have been newly diagnosed with breast disease. A breast care coordinator coordinates the care for each patient. A multidisciplinary team of surgeons, radiologists, medical and surgical oncologists, radiation oncologists and a plastic/reconstructive surgeon are scheduled to see each patient during a single visit if appropriate. A patient educator is available during clinic hours for patient education and risk assessment evaluation. Opportunities for clinical trial participation are offered to each patient as well.

Providers specializing in cancer center, cardiology, diabetes mellitus, epilepsy, osteoporosis management, Raynaud's disease, rheumatoid arthritis, osteoarthritis, and vascular disease offer gender-specific care to women and are part of the CoE's referral network.

The CoE has established a Women's Epilepsy Clinic that provides epilepsy management during pregnancy, catamenial epilepsy management, and other epilepsy-related issues unique to women.

◆ ***Magee Womens Hospital CoE***

Magee's Breast Evaluation and Cancer Prevention Center, a CoE affiliate, offers women, their families and referring physicians:

- Coordinated integration of a full-range of diagnostic and consultative services;
- Facilitated patient and physician access to informational and support services; and
- A multi-disciplinary approach for the detection and treatment of female malignancies utilizing the expertise of multiple specialists.

The Cancer Center offers the availability of a team of specialists including surgeons, gynecologic oncologists, radiologists, pathologists, medical oncologists, radiation oncologists and other health professionals. The team is dedicated to diagnosing, treating and supporting women suspected of having cancer and those diagnosed with cancer that are seeking treatment options. The multidisciplinary approach of providing all specialists in one location is a labor intensive, rewarding endeavor that results in the central focus being placed on the woman and her loved ones.

The CoE will maintain a role in the Bone Health Center by providing support at community screenings and promoting education. The Maintaining Healthy Bones Education Series was particularly successful with extra sessions scheduled. The five part series is for women who want to learn about the latest advances in the prevention, diagnosis, and treatment of osteoporosis. These sessions are free and include a complimentary buffet.

The Magee CoE initiated a Women, Infant and Fetal Heart Program. The heart program is dedicated to the prevention and treatment of heart disease in women and infants through the provision of medical care, research, education, and related support services. These services, to women and infants and the fetus with or at risk for developing cardiovascular disease, are

offered in partnership with the University of Pittsburgh Heart Institute. Three initiatives that have occurred thus far under this program are:

- To promote screening to support early detection of women's heart disease, Magee partnered with Pfizer Pharmaceuticals, who gave the program an unrestricted educational grant of \$10,000 to assist with the cost of conducting mass cholesterol screenings. Through a corporate partnership with Giant Eagle, they conducted mass screenings at four different Giant Eagle locations throughout the Pittsburgh area. Approximately 400 women participated in this program in 1999. The screenings continued in the fall of 2000. The CoE has attracted funding to supplement educational materials for this program.
- In effort to develop innovative approaches to the prevention, risk assessment, detection, early diagnosis and therapy of heart disease in women, the CoE instituted ***The Heart Check Program***, a preventive service offering women a complete cardiovascular risk assessment in order to identify baseline risk for heart disease. A nurse practitioner, which specializes in cardiology, conducts the evaluation and then offers individualized counseling and education on how best to reduce the risk. The program has been in effect since November of 1998. In order to make this program more accessible to a larger number of women, the program has partnered with Dupont Pharmaceuticals. Through an unrestricted educational grant of \$10,000, this service is now offered at a low cost of only \$10.00 (originally \$30.00). The CoE plans to continue an aggressive public relations print campaign started in order to publicize this service. In addition, they are planning a better tracking mechanism to

follow-up on these women. The response has been tremendous. In the fall of 2000, the center replicated Heart Check in the Neighborhood Centers so that it could reach African-American women and diabetics at greater risk.

- In order to develop, enhance and promote clinical diagnostic cardiology services at Magee, the Women's Diagnostic Heart Center was created so women could be tested on-site for heart disease. The nuclear exercise stress lab is now in full operation and has been for approximately the past six months. The center also provides echocardiology services on site and event recorders/heart rhythm monitoring as well.

◆ Indiana University CoE

The Indiana University CoE has hired a psychologist to be involved in a Clinic for Women with Disabilities. In addition to clinical responsibilities, the individual will be responsible for conducting studies related to satisfaction and outcomes of patients attending the clinic. The physician who oversees these clinical activities is a female Medicine/Pediatrics faculty member who specializes in disability issues affecting women throughout the lifespan.

The CoE hosts a Cancer Support Group for minority women which has been so successful that it had to be split into two weekly sessions to accommodate all participants. The addition of a bilingual coordinator will bring a Spanish-speaking support group.

◆ University of Puerto Rico CoE

The Center for Maternal-Infant Studies (CEMI), directed by Dr. Carmen Zorilla (a clinical provider at the CoE family planning clinic, a member of the Research Advisory Board and the PI of a

CoE research project that has received funding from the NIH Research Center for Minority Institutions Program) has been in existence for nine years and provides services both during pregnancy and beyond to women that live with HIV. One of its most important achievements has been the elimination of perinatal transmission in patients that they have treated. In addition to being very successful in preventing children of HIV mothers acquire the condition, it has developed an empowerment model to assist women in managing their condition and surviving. CEMI uses a multidisciplinary approach that combines Medical, OBGYN, Psychiatry, Psychology and Social Work. The Center is dedicated to research and training.

Clinical services offered by the CoE Women's Health Clinic include, as part of the patients first appointment, filling out a comprehensive health screening form and completing a depression scale prior to an evaluation by the clinic coordinator and a comprehensive evaluation by the primary physician. If necessary or requested, the patient's primary physician refers her to the CoE psychiatrist for an initial consultation, evaluation and recommendations. Patient's documentation is included in the patient's CoE Clinical Record. The CoE sponsors the first visit free of charge.

◆ University of Wisconsin, Madison CoE

The CoE has worked to develop clinical guidelines for osteoporosis and the management of the post-lumpectomy patients. These guidelines have been widely distributed on pocket cards and are available on the web sites of the University of Wisconsin Hospital and the VA Hospital.

The CoE is developing a comprehensive breast service model. The breast steering multidisciplinary committee is formally

looking at breast care services, best in practice and breast care delivery options. Ground breaking was in May and the building project has been initiated.

The CoE has worked to develop clinical guidelines for osteoporosis and the management of post-lumpectomy patients. These guidelines have been widely distributed on pocket cards and are available on the web sites of the University of Wisconsin Hospital and the VA hospital. In addition, fifteen outreach screenings for osteoporosis were completed and a hip fracture osteoporosis program was implemented.

A Women's Midlife Clinic opened at Meriter Hospital, which promotes women to be active partners in their own health care. This clinic was developed with the CoE. The Clinic primarily serves women between the ages of 40 and 64; however, women of all ages and cultures are welcome. Services are directed primarily toward women in the following phases of life: perimenopause, menopause and women of any age dealing with premenstrual syndrome. Professional services include: history and physical exams followed by the development of an individual preventative health plan specific to each woman's risk factors; laboratory and radiology services including peripheral bone density screening and nutritional counseling. Patrice Udelhofen, R.N., M.S., NP, works directly with each woman and their providers to assure optimum health in midlife and beyond. Ongoing follow-up care is provided. Accommodations for women with mobility disabilities and interpretive services are available.

The VA Women's Health Clinic, a satellite clinic of the CoE, received a grant to implement a Women Veteran Stress Disorder Treatment Team, with service in Madison and North Chicago. The creation of this team will provide four basic services: the

creation of local models of excellence in outpatient care at Madison and North Chicago with the help of associated Vet Centers; the provision of consultation for providers and patients throughout the VISN; the provision of ongoing education for providers via Web-based and telemedicine approaches; and the provision of ongoing psycho-educational and supportive services for patients with stress-related disorders.

The Women's Health Initiative was established in 1991, and the Madison branch was relocated to the UW-Women's Health Clinic. The PI also serves as Research Director of the CoE. The goal of the initiative is to address the most common causes of death, disability and impaired quality of life in postmenopausal women. Two studies of interest that are being conducted at this time are the WHIMS and WHISE projects. The Women's Health Initiative Memory Study was developed to assess the effects of hormone replacement therapy and the progression of symptoms associated with dementia. Over 7500 women nationwide have been enrolled and will be followed until the end of WHI's study in 2006. The Women's Health Initiative Sight Exam study has been designed to learn whether hormone replacement therapy can prevent or slow the progression of age-related macular degeneration, a major cause of blindness. Recruitment has begun to enroll over 5000 women nationwide over the next two years.

◆ University of Washington CoE

Three breast surgeons, an internist and a nurse practitioner staff the Breast Health Center. Mammography and ultrasound support services are located adjacent to the Breast Health Center in order to facilitate privacy and diagnostic expedience. Clinics are staffed by a breast-imaging specialist.

The Northwest Family Center, a CoE affiliate, cares for HIV positive women and children. Approximately 375 HIV positive women are seen per year.

The CoE partnered with Yakima Valley Farm Workers to develop a policy statement regarding risks of conversion to Type 2 Diabetes after gestational diabetes in the Hispanic farm worker population that includes plans for future needed interventions.

◆ University of California, San Francisco CoE (UCSF)

The Carol Franc Buck Breast Care Center at the Comprehensive Cancer Center, a CoE affiliate, is specifically designed to meet the needs of patients with breast problems, breast cancer, or general concerns about breast health. The multidisciplinary team of surgeons, oncologists, radiologists, psychologists, nutritionists, and pathologists work individually to help coordinate care to ensure women's needs are thoroughly addressed.

The Women's Specialty Program is part of the AIDS Clinic at UCSF serving approximately 600 HIV patients, 150 of whom are women. Eight physicians, eight nurse practitioners and midwives, three social workers, two vocational nurses, one nutritionist and one child psychologist are affiliated with the program.

The Positive Health Program serves 3,000 HIV patients, approximately 300 of whom are women. The program includes 20 physicians and five nurse practitioners and physician's assistants who provide HIV-related medical care to patients. Five psychiatrists, five social workers and one social work associate provide comprehensive psychosocial services.

◆ University of California, Los Angeles CoE

The Iris Cantor-UCLA Women's Health Center, which provides comprehensive women's health care, has two programs with special emphasis on women with chronic illness and disabilities:

- The Specialty Women's Clinic provides consultation for women with urinary incontinence, osteoporosis, and menopausal issues. Special emphasis is placed on developing appropriate plans of care for women with these issues who also suffer from chronic illness or disability, including frail and vulnerable elderly women.
- The Iris Cantor-UCLA Women's Health Center offers geriatric consultation by two faculty geriatricians who have special training in addressing disability issues, including frail and vulnerable elderly women.

◆ Tulane/Xavier Universities CoE (TUXCOE)

The CoE includes a dedicated Rheumatology Women's Health Clinic that provides care for women with rheumatoid arthritis, osteoporosis, osteoarthritis, lupus and other rheumatologic disorders.

The CoE is involved in Cardiovascular Medication and Lifestyle Modification (CALM), a behavior modification program to increase medication compliance in African American Adults.

Research

◆ Boston University CoE

The Program in Women's Health Research was co-founded and continues under the leadership of the CoE Research Director and CoE Co-director. The Program has continued in its goals to:

- Encourage, facilitate, stimulate and support multidisciplinary research programs in areas related to the health concerns of women
- Establish training and educational program in women's health
- Coordinate the research activities with BMC and BU on women's health
- Raise public and private funds for research on women's health
- Encourage and accelerate the translation of research results to health promotion, disease prevention and treatment

The Breast Cancer Working Group is the active arm of the division with 40 active members comprised of research scientists and graduate students from various departments of the School of Medicine. The primary focus of the working group is to present new research and new information by the members. This is done through Breast Cancer Working Group Seminar Series, which takes place on the average of once a month, usually attended by 25 members. At times, the BCWG also co-sponsors seminars with the Mass. Dept. of Public Health, Breast Cancer Research Program. Additionally, the BCWG attempts to inform its members of available funding for breast cancer research.

The following lists the recent clinical investigations supported by the CoE. The wide array of investigators and departments benefiting from this support are indicated by the affiliations listed for the Principal Investigators (PI).

- STAR: The Study of Tamoxifen and Raloxifen, (PI, Department of Surgery and School of Public Health) randomizing postmenopausal high-risk women to tamoxifen or raloxifen, with the primary outcome of breast cancer incidence reduction.

- **Exercise Effect on Mental and Physical Health in Breast Cancer** is a randomized trial of the structured physical exercise program vs. usual exercise during active therapy for Stage I and II breast cancer on physical and mental health outcomes, including weight gain.
- **The Gynecological Infections Through Study (GIFT)** (PI, Infectious Diseases). The multi-institutional observational study enrolls women at high risk for pelvic inflammatory disease (PID) and monitors the rates of PID. Primary outcome is to evaluate the risk of douching for PID.
- **IUD Study** Phase II study of a new intrauterine device for contraception.
- **New Techniques of detecting cervical pathology** (PI, Pathology). Comparative study of the efficacy of convention cytopathology, liquid based cytopathology and HPV typing through PCR to identify cervical cytology lesions in women.
- **Hormone Replacement Therapy and Skin Aging** is a study of the short effects of post menopausal hormone replacement on photo aging changes of the skin.

◆ ***Harvard University CoE***

The Center for Bone and Mineral Disorders offers expertise at all scientific levels from the bench to the bedside, and includes a unique basic scientist group with expertise in biochemistry, the chemistry of peptide and protein analysis, and molecular and cellular biology. The Center is undertaking basic and clinical research directed at furthering the understanding of osteoporosis, the hormonal regulation of mineral metabolism, approaches to the treatment of osteoporosis, and disorders of calcium

metabolism. Close interaction among clinicians and scientists with expertise in biochemistry and chemistry of peptides and proteins, molecular and cellular biology, *in vitro* and *in vivo* pharmacology generates a powerful and extremely competent capacity to provide a unique environment for interdisciplinary research. Information was presented from the investigations underway at this center at the CoE Research Day.

The CoE affiliated Gillette Centers for Women's Cancers include working committees, consisting of physicians from numerous specialties from all participating institutions, conduct a series of clinical studies in cancer treatments. Physician and laboratory researchers are pioneers in their work and success in the use of "combination chemotherapy" to treat many forms of cancer. The Center's researchers have also succeeded in the discovery and application of the CA-125 blood test for ovarian cancer.

The Dana-Farber/Harvard Cancer Center, a CoE affiliate, conducts clinical research, basic science research, and population research. Members of the Center include principal investigators and program leaders for cancer-related research grants. Investigators participate in clinical cancer research by developing protocols or by participating in clinical trials. To facilitate communication among the Harvard affiliated institutions, a Dana-Farber/Harvard Cancer Center Intranet has been established. On the Intranet, members exchange research results, critique each other's work, and review new findings while keeping information confidential. The Dana-Farber Cancer Institute formalized its affiliation with the CoE in 2000.

One of the CoE affiliate partners, Brigham and Women's Hospital (BWH), was selected as one of the 16 Vanguard Clinical Centers for the Women's Health Initiative study, with funding

support through 2005. In addition to assistance with study design and protocol issues, BWH enrolled more than 5,000 Boston-area women into the study. Two placebo-controlled interventions in the WHI are directly related to osteoporosis: (1) hormone replacement therapy arm (Premarin .625/Provera 2.5 mg. daily for women with intact uteri and Premarin alone if s/p hysterectomy vs. placebo), and (2) calcium and vitamin D supplements. The observational component of the study will also assess factors that modify risk for fracture in postmenopausal women. In addition to examining osteoporosis, the Women's Health Initiative is also designed to examine other diseases, including cardiovascular disease (CVD). Specific interventions being tested to reduce CVD risk include: (1) hormone replacement therapy, and (2) low fat diet: the benefit to risk ratio of low fat diet (less than or equal to 20% of calories from fat) versus the usual diet. The dietary modification also includes at least 5 servings/day of fruits and vegetables and 6 servings/day of grains. These interventions are also being tested for their effects on breast and colorectal cancer.

◆ University of Illinois at Chicago CoE

The CoE has convened research roundtables, which bring together researchers from across the University, who work on a particular topic. The roundtables provide researchers with an opportunity to engage in multidisciplinary discussions. In the first year of the contract, the roundtables focused on breast cancer, obesity/weight control, osteoporosis, cervical cancer, and HIV/STD. For the second year three topics were added: botanicals and dietary supplements, women's mental health, and adolescent health. Generally, the roundtables have a format in which the attendees each give a brief description of their current research followed by a general discussion.

One outcome of the first roundtable on breast cancer was the establishment of a listserv that would provide an electronic means of continuing communication among breast cancer researchers. Listservs are also organized for the osteoporosis and obesity/weight management groups. The listservs were used as a way of disseminating information about funding and conferences. The listservs have been combined into a single women's health research listserv. The listserv is used to send meeting notices and funding information; it functions as a way to maintain contact between the CoE administration and women's health researchers at the University. All the researchers identified as conducting research in an area related to women's health are subscribed. Several of the roundtables have resulted in the development of clinical protocols for breast cancer, cervical cancer, osteoporosis, and management of the obesity clinic.

◆ Indiana University CoE

The women's health research agenda for the CoE is as follows:

- Sexually transmitted diseases that disproportionately affect women
 - a) Chlamydia
 - b) Human papillomavirus
 - c) Adolescent STDs
 - d) HIV/AIDS
- Breast, Ovarian, and Uterine Cancer
 - a) Prevention and early detection
- Treatment and symptom control
- Adolescent Preventive Health Services

- Endocrinology/Rheumatology
 - a) Osteoporosis
 - b) Diabetes
 - c) Arthritis
- Aging
 - a) Cognitive activity
 - b) Diseases of aging

Areas of continuing active research relevant to women's health at Indiana University include: osteoporosis, sexually transmitted diseases, menopause, breast cancer, ovarian cancer, uterine cancer, hormone receptors, vascular biology, arthritis, hormone replacement, and development, to list just a few.

The CoE staff developed a University-wide research directory, which is in press. The collaborations between the IU NCI-designated Cancer Center and the CoE continue. RO1 funding in the areas of breast cancer screening and cancer diagnosis and survivorship issues involving women with breast cancer, ovarian cancer, and colorectal cancer include members of both groups. There are regular monthly programs and interdisciplinary mentorship opportunities with female faculty in diverse disciplines taking the leadership in research teams.

A grant for a Center for Enhancing Quality of Life in Chronic Illness (CEQL) was recently awarded to the Indiana University School of Nursing. The goal of the program is the improvement of health-related quality of life in people with chronic conditions throughout the lifespan. An infrastructure for collaborative research among scientists in the School of Nursing and in other health schools at the IUPUI is being developed. Training in teaching and research is provided, as is a pilot grant program open to the entire campus. The PI has long studied various

aspects of clinical and social issues affecting children with epilepsy and their families. Others involved, including the CoE Research Director, have collaborated on studies involving quality of life issues in women undergoing cancer treatment and in women who have survived these diseases, especially breast and ovarian cancer.

◆ Magee-Womens Hospital CoE

Aligning Regional Efforts with the National Health Care Agenda

This initiative will encourage individual investigators to conduct research and other project activities that align the Initiative's strategic direction with that of the national healthcare agenda. Individual investigators will develop grant proposals and respond to Requests for Proposals that are related to the broad aims of the Initiative. It is anticipated that the investigators-initiated health services, policy research, and research training projects will attract support from a variety of public, philanthropic, and corporate sponsors, both locally and nationally. An important objective is to address contemporary health concerns of the nation by gaining access to available funding. The CoE is involved in plans to examine the quality of care women receive from chronic conditions such as diabetes and heart disease as well as for special conditions such as breast or cervical cancer. Currently, the Initiative is conducting a pilot study designed to develop and test interventions for addressing domestic violence. The study will then be expanded to broader populations over the next one to two years.

◆ University of Wisconsin CoE

The CoE developed a monthly Women's Health Research Colloquia in 1999. Each month a basic or clinical scientist was invited to discuss his or her research, with commentary from

invited panel members from the research community with related interests. This has been well attended by a diverse group of clinicians and scientists. The fall semester conferences were developed along the theme of Women and the Immune System Mind-Body Interactions, and Breast Cancer.

◆ University of Washington CoE

The CoE established a web site for recruitment of participants into clinical trials (<http://www.medical.washington.edu/studies>). The site includes information for the public on commonly used terms in clinical research, describes phases of clinical trials and answers frequently asked questions about participating in a research study. Ongoing clinical trials at the University of Washington are also listed. Additional clinical care sites are sponsoring clinical trials including the Alzheimer's Center, Diabetes Care Center, and Cancer Care Center (found at <http://www.washington.edu/healthresearch/>).

The small grants program for the Center for Women's Health Research provides support to investigators in women's health to launch research and to conduct pilot studies which then lead to larger, extramurally funded proposals. Many of the projects are interdisciplinary and the program is open to investigators from all disciplines. Small grants include:

- Chronic Immune Activation and Hyperimmune Responsiveness in Fibromyalgia;
- Glucocorticoid Receptors in Women with Fibromyalgia; and
- Exploring cardiovascular risk in women who head single-parent families.

◆ Wake Forest University CoE

Twenty percent of all external funding at the medical center is acquired for research of women's health with the vast majority assessing chronic diseases and issues pertinent to older women. The CoE faculty and staff are involved in many research studies exploring chronic diseases including WHI, WHIMS, STAR, CO-STAR, WHISCA, and SWAN. The CoE also runs many breast, cervical, ovarian, and colon cancer protocols.

A Prevention of Cardiovascular Disease Among Diabetics clinical trial has begun that will include collaborations with women's health researchers and the CoE.

The CoE hosts an annual international conference on women's health. The topic alternates between heart disease and cognitive health.

◆ University of Puerto Rico CoE

The CoE Clinical Director is conducting a clinical trial comparing quality of life for women using Evista versus those using Prempro. Eligible women had to, among other qualifications, be 60 plus and have osteopenia or osteoporosis. Patients who showed clinical conditions were offered medical services even if they could not participate in the research, services that they would not otherwise have available to them.

The Multidisciplinary Clinic in AIDS Research was formed, a CoE affiliate and the first Women's Health Clinic dedicated to HIV infection research. A Data Analysis Center was established to identify potential clinical research areas in AIDS. Six multidisciplinary projects are underway in the Clinic. Enrolled patients benefit from access to research protocols that include

detailed immunological and nutritional evaluations and education.

The CoE has received funding from the NIH Research Center for Minority Institutions (RCMI) Program for supporting and overseeing two research projects as part of an eliminating health disparities initiative in two diseases affecting disproportionately Puerto Rican women: breast cancer and osteoporosis. The five-year project starts in October 2001:

- Project I: Multidimensional Empowerment Intervention Model for Women with Breast Cancer aims to implement a multidimensional model specifically designed for women with breast cancer. A diversity of psychosocial interventions have been designed and implemented in the USA, but none of these interventions has dealt with Hispanic women, or with Puerto Rican women. The impact of this model will be measured in short and long-term psychosocial, immune function and lifestyle variables. Significant contributions of this project include establishment of a longitudinal cohort of women with breast cancer; and correlation of survival, cytokines, empowerment levels, psychological and behavior outcomes in two distinct groups: an intervention and a control group. Cross-section and longitudinal outcomes will be correlated for the most relevant factors.
- Project II: Health and Menopause in Hispanic Women in Puerto Rico will develop the first data of the health status, during midlife and menopause, of Hispanic women living in Puerto Rico. It will assess the prevalence of osteopenia and osteoporosis, using bone densitometry of the calcaneus and DEXA of the hip and spine when indicated; correlate bone density with state of menopause adjusting by lifestyle patterns

and will estimate the parameters of the menopausal transition in Hispanic women living in Puerto Rico. Despite evidence that substantial morbidity is associated with the age of transition to menopause, data on menstrual, hormonal, metabolic and risk factor changes during this transition are scarce and for Hispanic women virtually non-existent. A study of Hispanic women living in Puerto Rico will offer unique opportunities for understanding factors associated with changes in health status during midlife. As Puerto Rican women experience high rates of both obesity and diabetes, studies in this population may be particularly informative about the impact of mid-life change on these and related disease processes. Since no data on the experience of perimenopause and menopause in Hispanic women living in Puerto Rico has been published, the development of an epidemiological profile of Hispanic women (ages 35-80) regarding bone densities, midlife menopausal transition, health status and lifestyle practices is needed.

- Project III: Another component of the project involves the CoE facilitating and promoting the development of multi and interdisciplinary research on campus and promoting collaboration and interaction among campus basic and clinical researchers across disciplines already conducting research projects in women's health. The specific aims of this activity are: to encourage and facilitate new investigators in examining research areas pertinent to women's health, to facilitate young women investigators in competing more favorably for external research funds, to promote interdisciplinary collaboration in the development of research projects in women's health, and to enhance interaction among investigators with ongoing research in women's health.

The CoE Director has received funding from the American Heart Association to study Cardiovascular Risk Factors in Hispanic Women living in Puerto Rico. The Project aims to provide pilot data for the development of a longitudinal study on the prevalence of risk factors for cardiovascular disease and other conditions affecting women's health and their relationship to menopausal status. The CoE Clinical Director will be the clinical director of the study. The major goal of the study is to develop an epidemiological profile of Hispanic females aged 35-80 regarding the prevalence of major risk factors for cardiovascular disease by health statute, demographic characteristics and menopausal status. A 20 minute self-administered questionnaire obtains information on demographic, prevalence of chronic illnesses such as hypertension, diabetes and osteoporosis; lifestyle practices including use of tobacco, alcohol and level of physical activity; current and past use of hormone replacement therapy and alternative medicine; gynecologic and obstetric history and use of attitudes toward health screening. Participants will be screened for blood pressure, weight, and height, body composition measurements using a bioelectrical impedance body composition analyzer. A blood test will be drawn for determination of menopausal status by FSH measurements. Triglycerides and fasting blood sugar and lipid profile will also be measured. Data derived from the proposed study will promote research on cardiovascular disease in women.

The CoE Clinical Director conducted research on the "Comparison of Raloxifene Hydrochloride with Continuous Combined Hormone Replacement Therapy in Relation to Breast Tenderness and Other Compliance Surrogates in Post Menopausal Women 60 Years of Age and Older" between January 2000 and June 2001. Eligible women had to, among other qualifications, be 60 plus and have osteopenia or osteoporosis.

Patients who showed clinical conditions were offered medical services that otherwise would not have been offered to them. All received a physical examination, PAP smear, mammography, DEXA scan and an endovaginal Ultrasound on visit.

Funding has been awarded through a clinical research grant from a pharmaceutical company to study the effect of PTH (parathyroid hormone) vs. Fosamax in post-menopausal women with osteoporosis. Ten women from 45 to 85 years with clinical diagnosis of osteoporosis will be followed for 24 months while receiving PTH or Fosamax. The study will be double blind; placebo controlled, and will be conducted at the Medical Sciences Campus Clinical Research Center at the University Hospital. The primary investigator of the study will be Dr. Ivonne Z. Jimenez, a clinical provider at the CoE. Dr. Lillian Haddock, member of the CoE Clinical Advisory Committee and a clinical provider at the CoE clinic, will be the project consultant. Recruitment began in April 2001.

Six multidisciplinary projects are currently conducted in the Center for Maternal-Infant Studies (CEMI—see reference under Clinical Care). Patients enrolled in the clinical studies benefit from access to research protocols that include detailed immunology and nutrition evaluations and education.

◆ University of Michigan CoE

The CoE registry project is working with the interdisciplinary cervical cancer research team to create a registry with information on all abnormal pap smears and colostomy results so that these women can be tracked and their outcomes recorded in the hope that the additional information will help researchers determine effective protocols for follow-up of abnormal paps and cervical cancer prevention.

◆ University of California, San Francisco CoE

The CoE has created a Center for Women's Health Research focusing on 12 research areas including:

- Cardiovascular
- Breast cancer
- Skeletal health
- Neuropsychiatric disorders (dementia and depression)
- Substance abuse
- Urinary incontinence
- HIV in women
- Sex hormones
- Women's imaging
- Complementary and alternative medicine
- Health services research
- Aging

The UCSF National Cancer Center includes a clinical cancer center and a cancer research building. The Center's mission is the discovery and evolution of new ideas and information about cancer, from the research to the clinical implementation phases of cancer control. The Center's unique structure encourages collaboration between clinical and lab scientists, thus fostering the translation of laboratory discoveries into new therapies for improved patient care.

The Bay Area Breast Cancer Translational Research Program sponsors research in four general areas: epidemiology, cancer genetics, cancer biology and molecular therapeutics. Clinical services with extensive clinical trials opportunities are available to women with breast cancer through the UCSF Breast Care Center projects.

Medical Effectiveness Research Center for Diverse Populations (MERC) conducts outcome research on the appropriateness and effectiveness of health services and procedures provided to minority populations, provides education and training opportunities in health services research, facilitates collaboration and provides technical assistance, and disseminates research findings about the health needs of minorities and what interventions and styles of care work best for minority populations. Current research is being conducted on cancer, cardiovascular disease, and reproductive health.

The Center for AIDS Prevention Studies (CAPS) promotes collaboration and multidisciplinary research on the prevention of HIV infection and disease. Primary prevention is being supplemented by research on secondary prevention—ways to delay the progression of disease, reduce its severity, and cope with its psychological and social consequences.

The AIDS Research Institute was created to work to forge significant scientific advances to prevent, understand and treat HIV infection. The center is charged with the overall responsibility for AIDS research program planning to integrate basic, clinical, and prevention activities at the UCSF.

The Bay Area Perinatal AIDS Center combines research and care for HIV-positive pregnant women. The program has eliminated mother-to-child transmission of HIV through use of

combination antiretroviral therapies, as well as counseling and support, careful monitoring and ongoing expert care.

The Osteoporosis and Arthritis Research Group maintains a high profile in the international scientific community as a diverse center of technical innovations and clinical research endeavors in the diagnosis of metabolic bone disorders and orthopaedic imaging.

The Bay Area Research Consortium for Women and AIDS is a local research group overseeing research on women and AIDS. One study, the Women's Interagency HIV Study, is investigating the clinical, laboratory and psychosocial aspects of HIV infection of women in a multi-site, prospective fashion.

A CoE member worked with a multidisciplinary group to publish an American Heart Association/American College of Cardiology Consensus Scientific Statement on Preventive Guide to Cardiology (Circulation 1999, Journal of the American College of Cardiology 1999).

◆ University of California, Los Angeles CoE

The CoE program has special emphasis on research in the areas of chronic illness and geriatrics, including disabilities faced by elderly women. The Yoga for Kyphosis study, based at the CoE, studies the effects of yoga on the functioning of older women disabled by osteoporosis and/or osteoarthritis.

The Breast Cancer and Menopause Study (CAMS) evaluates the biological, psychological, and social consequences of menopause in breast cancer survivors, with special attention to the effects of chemotherapy. The CoE also houses studies examining the effects of antiretrovirals on HIV infected women, and the effects

of inhaled treatments for chronic obstructive pulmonary disease on bone density in women.

Three training grants, the UCLA Building Interdisciplinary Careers in Women's Health grant (UCLA BIRCH), the Hartford Center of Excellence in Geriatrics, and the K-12 in Geriatrics from the National Institute on Aging, support training of researchers in areas relating to chronic illness in women, including dementia, depression, and osteoporosis.

◆ Tulane/Xavier Universities CoE

The Xavier University Clinical Trial Unit initiated or completed studies to address disease areas that have a high incidence and prevalence within women or the minority populations including, hypertension, irritable bowel syndrome, congestive heart failure, pneumonia, and erectile dysfunction.

The Child and Adolescent Trial for Cardiovascular Health for elementary school children includes 3rd through 5th grade classroom curricula and home-based extension activities, environmental modifications and physical education, and tobacco-use policies.

The Heart Smart Family Health Promotion is a school-based clinical model for cardiovascular risk reduction for high-risk children and their parents which included positive eating changes, improved 1-mile walk/run times, increase in parent's leisure physical activity and health knowledge, reduction in blood pressure and tryglyceride levels.

The Bogalusa Heart Study is a source of data collection in progress assessing cardiovascular risk in women. In addition, the clinical cardiology inpatient service is being utilized to assess the

clinical characteristics of women for ischemic heart disease.

◆ MCP Hahnemann CoE

One of the junior faculty members has established a research portfolio examining cardiovascular risk factors, particularly in minority populations. Projects include: (1) a project to examine non-traditional risk factors in cardiovascular disease in the primary care population; and (2) working to develop small research proposals concerning the cardiovascular disease that is so prevalent in the female population.

“Listen, Little Sister,” allows for collaboration with Pediatrics and HIV/AIDS service to incorporate the perceptions of HIV/AIDS patients into STD/HIV risk reduction education for teenagers.

Community Outreach

◆ Harvard University CoE (HU)

The CoE collaborated with Boston University’s CoE to create a Directory of Women’s Health Resources in Boston. The directory includes 26 women’s health categories that contain resources and referral organizations in the Boston area for provider and patient information. The categories covered in this directory include the following: abuse (domestic violence and sexual assault), advocacy/policy groups, breast cancer resources, cancer resources, eating disorders/obesity, government resources, HIV/AIDS and other sexually related conditions, menopause, mental health, nutrition and exercise, occupational and environmental health issues, osteoporosis and arthritis, preventive health, reproductive health and pregnancy, smoking cessation, and substance abuse and addiction. In addition, there are categories dedicated to specific groups such as adolescent health, elder women, homeless women,

incarcerated and previously incarcerated women, lesbian and bisexual resources, uninsured/underinsured women, women as caretaker, women of color, and women with disabilities.

One of the CoE affiliate partners, Brigham and Women's Hospital (BWH), received funding from the Osteoporosis Business Fund to explore minority women's understanding of osteoporosis and their assessment of educational materials. Women who participated in the Minority Women's Health Journal project reviewed information about osteoporosis. In addition, lay health advisors from the WELL program conducted focus groups with minority and other women to better describe their understanding about osteoporosis and its prevention. They found that most materials are written at too high an educational level for women in the community, that women were unaware of their risk for osteoporosis, that women do not know how to increase calcium intake in their diets, and that young women do not consider osteoporosis to be a problem. They used information from this process to develop health tips for osteoporosis for the Minority Women's Health Journal.

In the spring of 1997, BWH, one of the CoE affiliate partners, launched its Lecture Series program. Doctors, nurses, nutritionists, and other health care professionals from BWH hold lectures and discussions in the spring and fall about various health topics. These seminars are designed to bring valuable health information and resources to community members—specifically women—in Boston's suburbs. Throughout the course of the program, BWH has been able to reach over 1,800 women. Seminars include topics such as osteoporosis awareness, treating menopause, and cardiovascular disease in women.

A CoE affiliate, the Women's Health Committee at Massachusetts General Hospital (MGH), held a women's health symposium in

October 1998, “Staying Well: Good Health for Women at Every Age,” in November 1999, “Bridging the Gap: Alternative and Complementary Medicine,” and in May 2000, “Caring for the Heart: Educating Women about Heart Disease.”

For the past two years, the CoE has participated in a campaign called the “Boston Heart Party” to educate local women about the prevention of cardiovascular disease. The program included screenings, information about cardiovascular disease risk factors, and heart health management tips for women. The Boston Heart Party screenings were held at more than 60 sites in and around the Boston area and were administered by health care professionals from Partners HealthCare System, Inc. (BWH and MGH), Care Group, Inc. (BIDMC), and the organizations’ affiliated health centers. Screenings included blood pressure measurement, cholesterol and glucose testing, and individualized risk factor profiles. The results were given to each woman at the time of the screening, and physician referrals were provided upon request. The screenings were open to all women free of charge. Publicity for the Boston Heart Party included television and newspaper advertisements, web site listings, and mailings to hundreds of thousands of Bostonians.

The 1999 Heart Party campaign ran from Valentine’s Day through Mother’s Day. Over 2,300 women were screened. Seventy-one percent were White, 8% were other, 7% were Black, 5% were Hispanic, 4% were unknown, 2% were Asian, 2% were American Indian, and 1% were Asian-Pacific Islander. The average age of participants was 56. Thirty-one percent were smokers. The average income level of participants was \$48,000, 25% had a high school education or less, 36% had some college, and 39% were college graduates.

An advisory group was formed within the CoE to discuss how to improve the Heart Party program for the 2000 campaign. The 2000 campaign ran between the first day of spring and Mother's Day. More than 2,300 people screened, of which 77% were women. Sixty-nine percent were White, 10% did not answer, 8% were Asian, 5% were other, 4% were Black, and 4% were Hispanic. The average age of participants was 53, and 89% had some form of health insurance. Seventy-six percent were non-smokers, 7% were former smokers, and 10% didn't answer.

◆ Indiana University CoE

The CoE sponsors and participates in programs for the elderly and for individuals with chronic health conditions, with University faculty and staff as speakers. The disability expert frequently presents talks to community groups on women's issues. In addition, the Cancer Center has support groups for survivors of breast and cervical cancer, as well as genetic counselors who can address family issues concerning inheritance of specific cancer-associated genes; and the women's HIV/AIDS Clinic has a monthly group meeting for patients at which topics relevant to their long-term health and well being are discussed.

Members of the CoE have been invited to speak to participants on health issues for women who have survived ovarian cancer at the Fourth Annual Ovarian Cancer National Alliance Advocacy Conference, scheduled in Indianapolis for September 12-19 in conjunction with the meeting of the American College of Obstetrics and Gynecology.

◆ MCP Hahnemann CoE

The MCP Hahnemann University CoE is working with Latinos with disabilities and stroke prevention in the context of the Pick Your Path To Health Campaign (an OWH

sponsored public education campaign designed to help women take simple steps to improve their health and to provide tools for local communities to promote practical, culturally relevant action steps to wellness).

The Breast Center, a CoE affiliate, has established interdisciplinary session for patients after diagnosis of breast cancer. Women have the opportunity to discuss their situation with a medical oncologist and a radiation oncologist during the same session.

Physicians from the MCPH centers, including the CoE, gave a workshop at the American Heart Association “Silent No More,” an event specifically designed to raise awareness of cardiovascular disease in African American women.

◆ ***Magee-Womens Hospital CoE***

The Magee-Womens Hospital CoE participates in community outreach projects and conferences to support women with disabilities and improve their access to healthcare that meets their specific needs. To meet the challenge disabilities bring to women and to the health care setting, Magee, under the direction of its CoE Outreach Director, will educate its staff at three levels to include:

- Awareness by all employees;
- Professional training to assure sensitivity and competency in caring for women with disabilities and their families;
- The development of experts to provide consulting services both within the organization and the community.

The Magee-Womens Hospital CoE has developed a sex education program for families of children with disabilities. The

educational outreach is coupled with the CoE's new program for women with disabilities. The program will provide more comprehensive services and education for mature women such as menopause support and the prevention and treatment of urinary incontinence.

The CoE's Breast Cancer Education Series, launched in 1998, consists of lectures designed for all individuals seeking up-to-date information about breast cancer - breast cancer survivors, women recently diagnosed with the illness, or women and their family members concerned about the disease. The goal of the program is to provide information to women and their loved ones, to help them understand the illness, its treatments, and what to expect from the healthcare system. This years lecture series is scheduled through to January 2001.

The program addresses a variety of topics related to breast cancer, such as coping and communication methods, risk identification, prevention and detection techniques, and treatment options. Up-to-date information is presented by a variety of breast cancer experts followed by a question and answer session. The program supports an "ask the expert" format to fully meet the educational needs of each participant. Participants have the opportunity to learn from the breast cancer experts as well as from other participants' experiences and exchange of information.

◆ Tulane/Xavier Universities CoE

The Tulane/Xavier Universities of Louisiana CoE collaborates with the Association of Retarded Citizens (ARC) to establish a series of discussion groups addressing pertinent health issues. The program is tailored for the special needs of this population.

The CoE includes brochures on topics important to women's health in all Women's Health Clinics. Brochures are available on

women and heart disease, osteoporosis, diabetes, and a variety of other health issues.

The CoE partners with the National Black Women's Health Project in bringing together organizations with expertise in implementing community based health promotion programs and conducting health related research for CDC's REACH 2010 program (designed to develop a community intervention to reduce the prevalence of Cardiovascular Disease risk factors experienced by African American women).

The CoE developed a lecture series for a local shelter for homeless substance users. Subjects addressed included breast health, heart disease and stroke.

The CoE web site has been expanded to include education resources in Women's Health and with numerous women's health website links, including Women and AIDS: A Disease of Poverty. Additional web links include those addressing topics such as breast cancer and cardiovascular health, disability, and osteoporosis.

The CoE is working with Latinos with disabilities and on stroke prevention.

◆ University of Pennsylvania CoE

The University of Pennsylvania CoE conducted focus groups in an effort to establish a community outreach program that overcame current barriers to health care and optimized the use of visually and linguistically accessible information pathways for Deaf women to empower them to become informed and effective consumers and self-advocates of health care services. Specific program goals included:

- To provide training and support to deaf women to empower them to become informed consumers of health care services and advocates for themselves; and
- To provide direct dissemination of women's health information to deaf women.

The University of Pennsylvania CoE launched the Health Tip Card project in March 1999. It is an innovative and creative vehicle to provide health information to African-American women in a way that is both informative and emphasizes the role of the woman in taking preventative measures to ensure the healthiest of lifestyles. The bottom of the Health Tip Card is perforated with a Heart Healthy recipe on one side and available community resources on the other side. If a woman takes the card for the recipe, she is also getting a list of resources that she may otherwise not know exist. The educational materials are widely distributed to practice sites throughout the Health System. Materials also are being distributed through preventative collaborative efforts with various community programs. It is estimated that over 30,000 women will receive the Health Tip Cards. Information contained was developed through the use of focus groups in West Philadelphia to establish the needs and knowledge of the immediate community service area. The educational materials created are culturally sensitive to African-American women to address the dearth of such health information in existing literature are culturally sensitive to African-American women to address the dearth of such health information in existing literature. Topical examples of the Health Tip Card include:

- "Breaking the Silence-Women and Cardiovascular Disease"
- "Breaking the Silence-Surviving Cancer & Women of Color"

◆ University of Michigan CoE

The Michigan University CoE has developed a Women's Health Program Diversity Initiative to conduct prejudice reduction workshops that foster understanding across various dimensions of diversity including disability.

The CoE Resource Center developed a lecture series covering a number of health topics delivered in a "medical school" fashion by health care practitioners. Sessions consisted of two presentations. Subject matters include: uterine leiomyomas, endometriosis and osteoporosis.

◆ University of Wisconsin, Madison CoE

The University of Wisconsin at Madison CoE's outreach affiliate, the Buchler Project, participates in the Dane County site of the Women and Mental Health Study, working to improve public sector mental health services for women with psychiatric diagnoses and trauma histories. Consumers, including those with serious long-term disability are active participants in the project.

The CoE has sponsored several community events for patient information, including: Women and Heart Disease, Women and Cancer, and the Women and Midlife Series. CoE staff also were involved in the development of a treatment decision-tree software program for breast cancer patients.

The CoE web site links to consumer web health resources and local osteoporosis working group diagnosis and treatment consensus information (a local group of health professionals who discuss and promulgate standards of osteoporosis diagnosis and treatment).

The Witness Project is a health program to raise breast cancer awareness among African American Women. The program is implemented in churches and community centers. Women involved in the program “witness” about their triumph over breast or cervical cancer, and health instructors teach about early detection. They answer questions about mammograms, pap tests, and signs and symptoms of breast and cervical cancer. Together they send the message to other African-American women that cancer doesn’t have to be a death sentence. The Madison Witness Project has been a partner with the CoE, and is preparing to spread its programming to Beloit and Milwaukee.

Patricia Harris, MD, MS who completed her Women’s Health Fellowship with the CoE, published a paper describing the results of a survey of breast cancer survivors. Estrogen alternatives that the women are using to manage menopausal symptoms are explained.

Katie Hanson, an undergraduate student intern at the CoE, developed a website for teens on adolescent idiopathic scoliosis. This project collects stories from women of all ages who had surgery to correct adolescent idiopathic scoliosis. It is designed to provide information and encouragement to those facing scoliosis surgery and those who care about them. It is also for those who are post-surgery and curious about what to expect in the future.

◆ Wake Forest University CoE

The CoE established “Health at the Well” at two libraries in the Forsyth County Library System. A multitude of resources are available at the library for people in the community to access at their convenience including books, magazines, journal articles, and brochures. A new topic is covered every other month. Activities include a forum entitled, “Diabetes, Cancer and Heart Disease.

The CoE coordinates with the Director of the Hemophilia Center, utilizing brochures on Von Willebrands Syndrome for distribution in clinics and requesting the Service Line to address referrals to the Hemophilia Center.

A Women's Health Seminar Series Agenda includes: The Genetics and Epidemiology of Lupus, Monitoring Treatments for Osteoporosis, Hormones and Heart Disease and Ovarian Cancer.

A directory of community resources has been developed to provide individuals with a list of educational and community programs related to women's health within Forsyth County and North Carolina. Sites include: American Heart Association's Women's Website; Cancer Information Service; Cancer Services, Inc.; Department of Family and Community Medicine: In control: Taking charge of Your Diabetes; and Family Heart Symposium.

◆ University of Puerto Rico CoE

The CoE educational program MujerEs, a comprehensive educational program for both health professionals and consumers was inaugurated in March 2000. The main component of the program consists of a Conference Hall on Wheels that tours the Island offering conferences on women's health, videos and densitometry tests free of charge. The Conference Hall on Wheels is a mobile, air-conditioned facility with screen, projection equipment, tables, seating capacity for 40 persons, and a separate space for taking densitometry measures and storage space. Conference topics offered by health professionals include: menopause, family planning, vaccines, depression in women, pain management, breast cancer, hormone replacement therapy, osteoporosis and cancer detection. The program also includes annual continuing education symposia for physicians and for

consumer education. The CoE Center Director is responsible for helping coordinate the requests for the van appearance and identifying speakers for the conferences. A brochure describing the scope of the program is distributed at all of its activities.

The Women and Health Center publishes the *Mujer & Salud* newsletter in Spanish. This newsletter covers topics of relevance to Puerto Rican women's health. The information is organized in a clear, concise way and female faculty members write most articles. The biannual publication targets a diverse and broad audience of readers. It is distributed free of charge to the academic community and to government and non-governmental organizations and has been uploaded as a link in the Center's Homepage. Already in its fifth year, it has addressed diverse topics such as women's health statistics, menopause, breast cancer, adolescent health issues, domestic violence, healthcare needs of minority groups, and women's participation in the health fields.

The CoE has been involved in the production of brochures, one on Breast Cancer Self Exam and another on Osteoporosis. The topics of the brochures were based on two of the most pressing information needs of women from a surveyed population. The brochures, originally in Spanish, have been translated into English and are available on the web. Information, included in the breast self-examination brochure was displayed in a poster exhibited on Campus and is now part of the educational materials exhibited at the Conference Hall of Wheels of the CoE educational program MujerEs.

The CoE prepared three new brochures in Spanish for distribution in the Neuroscience Health Fair held in Plaza Las Americas. They were done in an effort to collaborate with a better understanding of the more prevalent conditions related to

the brain and neurological system in females. Topics of brochures were depression, multiple sclerosis and fibromyalgia. Health Education students that were doing their practice at the Center and the CoE Education Coordinator prepared the brochures.

The CoE collaborated with the Alliance for the Promotion of Mammography by producing 5,000 copies of a special issue of the newsletter ***Vida Saludable*** dedicated to Breast Cancer. The publication content, which includes an article by the CoE Center Director, was prepared by the Alliance. Funding for printing was provided by an educational grant to the CoE from a pharmaceutical company.

The University of Puerto Rico convened a Diabetes Mellitus Education Clinic in an Effort to increase awareness of diabetes and provide information on its prevention and care to patients in the CoE clinic. A certified diabetes educator and a nutritionist conducted the clinic.

During the month of October, the CoE holds a Mammography Clinic for employees of the Medical Sciences Campus, in coordination with the Oncology Hospital and the School of Medicine. During this annual event, participants register at the CoE where they are given referrals and appointments for screening mammograms. Mammograms (and sonograms, if necessary) are performed at the facilities of the Oncology Hospital. The Hospital sent results to the CoE for distribution to participants. The CoE coordinates the distribution of results and appointments with physicians at the CoE clinic for those women interested in clinical examinations and for follow up on findings. If participants had personal physicians outside the CoE clinic, they are required to fill out a form indicating that they would discuss findings with them. The activity has been effective in

increasing awareness of the need for screening measures for breast cancer and the number of participants in the screening clinic has gone up each year. As a complement to this activity and information booth is also held during October to increase awareness on breast cancer issues, to promote preventive and early detection measures, answer questions and teach breast self exam. The activity attracts members of our academic community, patients and other campus visitors.

October 18, 2000 marked the first time that the International Menopause Awareness Day was commemorated in our Campus. The CoE, in collaboration with the Menopause Information Center of the School of Medicine, held an information booth for women attending the Center of Excellence Clinic as part of the activity, and in collaboration with the School of Medicine Department of Psychiatry, residents held a clinic to screen for depression.

The CoE sponsored "Between Women" an educational activity on prevention/early detection of breast cancer, menopause, perimenopause and osteoporosis at the San Juan Federal Prison. The program was directed to provide health prevention information to female inmates.

The Second and Third Congress for Mastectomized Women were held in Cataño in March 1999 and 2000. The event aims to provide information and support to women who have undergone mastectomy and their significant others. The activity is sponsored by several local organizations and the CoE has collaborated in the promotion and in providing speakers for the event. Conferences related to physical, mental and emotional aspects of breast cancer and its treatment. At the Second Congress, the CoE Center Director presented conferences on the use of estrogen in breast

cancer patients and on the characteristics of breast cancer survivors.

The CoE Associate Director is actively participating in a Task Force: Citizens Coalition for Nursing Home Reform that seeks to achieve quality in long-term care for aged Puerto Ricans in need. While the number of persons in this type of facility of care is only approximately 8,000, island-wide, most of them are women and the quality of care is low. In collaboration with the CoE a representative of the AARP (American Association of Retired Persons) convened the group that started meeting in March 2001. The group intends to help coordinate work among all concerned governmental and nongovernmental institutions, and promote all necessary legislative efforts in order to achieve its goals.

A student from the Health Education program at the College of Health Related Professions, assigned to the CoE to do her practice developed an educational program on Asthma- "Helping you control your asthma." Participants met for one-hour sessions every Tuesday for 8 weeks. Different topics on the subject were presented either by the student or by an invited resource. Topics included were: living with asthma; taking care of your respiratory system; the environment that affects you; use of medications before, during and after an asthma episode; nutrition and asthma; alternative medicine for asthma; meditation and relaxation for asthma control.

◆ University of California, San Francisco CoE

The Breast Care Center has a comprehensive website illustrating all aspects of breast cancer diagnosis, treatment, research and other areas of concern for patients and their families. The site includes among its 150 individual pages detailed information

about every aspect of a patient's treatment at the Breast Care Center, an exhaustive section on clinical trials including a comprehensive glossary of breast cancer clinical terms, a list of links to other sites divided into subjects, and a navigation path that assists patients to quickly find their way to the information they need based on their individual situation.

"Harmony and Health: The Promise of the New Millennium" was the focus of the CoE's 7th annual Women's Health 2000 symposium. The symposium featured 30 sessions on topics including heart health, ovarian cancer, and osteoporosis.

The Gyn Oncology program is a multidisciplinary team of physicians and health care staff to meet the special needs of patients with cancers of the reproductive system. The team advises patients and their families of the latest treatment options available and offers timely innovated, and compassionate care in a personal and supportive environment.

◆ University of California, Los Angeles CoE

The "Heart Gram" is an educational tool that lists the signs of heart attack for women and encourages others to "help protect the hearts of women you love by sharing the warning signs of a heart attack." Originally intended as a Valentine's Day educational promotion, the Heart Gram proved so popular that it is distributed year-round, including at community sites.

Packets of information for women newly diagnosed with breast cancer are distributed throughout the UCLA Healthcare Network, ensuring that appropriate information is available regardless of site of diagnosis. The packets include up to date information, which can be given to women at any or multiple points of their diagnosis and treatment.

The CoE presents lectures to the community on topics reflecting comprehensive women's health education. Those presentation topics related to chronic illness and disability included osteoporosis, cancer, depression and mood disorders, and cardiovascular disease.

The CoE developed and implemented the "BONE" exercise program (Beat Osteoporosis Now Exercise program) This 10-week program was developed in conjunction with UCLA faculty experts on women's health and osteoporosis. The Program was geared for women ages 55 and older.

The CoE is conducting a study on Hatha Yoga for women with kyphosis (forward curvature of the thoracic spine) to determine if 3 months of twice a week Hatha Yoga classes can help improve kyphosis and breathing difficulties associated with kyphosis.

The CoE Community Alliance is comprised of a variety of partners who meet at the Center on a quarterly basis. Partners include members of established community organizations, "grass roots" organizations, and programs/departments within UCLA that serve select women's populations. Alliance activities have provided a two-way flow of information. Presentations by UCLA faculty on the newest information on women's health topics are given, as well as, when appropriate, information on recruitment for clinical trials. The partners then distribute this information to their community members. Partners also express the unique concerns and needs of their populations as they related to the particular topic presented. Presentation topics have included mammography, the STAR Study (research study of Tamoxifen and Raloxifene), depression and overcoming barriers to clinical services for women with disabilities. Community partners include those involved with offering education and services to women with HIV/AIDs, ovarian cancer and disabilities.

Professional Education

◆ Boston University CoE

The Boston University CoE conducted an extensive evaluation of the first and second year medical school curriculum, and the presentation of women's health issues within the curriculum. The analysis identified several areas with no or poor gender specific information included in the curriculum.

The CoE took the next step to address the gaps in the undergraduate curriculum. Meetings with the CoE Center Director and Associate Dean and Chair of the curriculum committee focused on a methodology of implementing curriculum change. Three initial areas were selected for curriculum revision: cardiovascular disease, incontinence, and diabetes.

The CoE and the Department of Obstetrics and Gynecology presented a Women's Health Issues-2000 ***Postgraduate Course*** in November 2000. The course updated specialists and generalists on recent advances in women's health. A few examples of the discussions that were provided at the program include: Stress Induced Anovulation, Cardiovascular Disease and Hormone Replacement Therapy and Advances in Estrogen Biology.

◆ University of California at San Francisco CoE (UCSF)

The University of California at San Francisco CoE Core Women's Health Knowledge Competencies includes: Finances & Women with Disabilities; Occupation and Women with Disabilities; and Sexuality & Women with Disabilities.

The CoE co-chaired a conference "Heart Disease in Women: Where are we Now? Where are we Going?" which provided a broad overview for the practicing internist, cardiologist, primary

care practitioner, nurse, or obstetrician/gynecologist. New information was provided from a variety of clinical trials, conferences, and expert opinion on how to prevent and treat heart disease in women.

The CoE helped to develop a course, “Controversies in Women’s Health,” designed for family physicians, internists, gynecologists, nurses, pharmacists and all others involved in providing quality health care for women. The course provides a practical update on a full range of common but controversial issues in women’s health. Emphasis was placed on new developments in preventive care and cardiovascular risk factors in women, among others.

◆ University of California, Los Angeles CoE (UCLA)

Residents in both internal medicine and obstetrics and gynecology train at the CoE, participating in the multidisciplinary Specialty Women’s Clinic evaluating issues relating to menopause, osteoporosis, and urinary incontinence.

Conducted the 16th Annual Intensive Course in Geriatric Medicine and Board Review in the fall 1999. Approximately 220 physicians, nurse practitioners and physician assistants and 40 pharmacists attended addressing specific women’s topics including heart disease in women, osteoporosis diagnosis and treatment, urinary incontinence, breast cancer, stress, sex and the Hippocampus.

◆ University of Illinois at Chicago CoE

The University has a graduate program in Disability Studies, offering Masters and PhD degrees. There is excellent participation of faculty from this program in CoE efforts, including the Women Friendly Services Task Force which is working to improve services for all patients and particularly for underserved groups.

◆ Indiana University CoE

The CoE presents talks for all members of its professional community on specific problems of women with disabilities, as well as lectures on osteoporosis, cancer in women, arthritis in women, heart disease, menopause, etc.

◆ University of Washington CoE

The Osteoporosis Education Project features a web-based outreach format to improve access to information for health care providers serving high-risk minority communities and the under-insured in the Puget Sound region. Physician- and nurse-educators, physical therapists, dietitians, and experts in adult education have been involved in the planning and execution of the project. Evidence-based, readable and culturally sensitive materials are being developed on nutrition and other life-style interventions, as well as medical therapies used in treatment and prevention of osteoporosis. The project web site is located at <http://www.osteoad.org>.

A content editorial board has developed cases for inclusion on an interactive site for residents and students that addresses all aspects of screening, treatment, epidemiology and pathophysiology. A prototype module on cervical cancer was first created in order to work out programming and education issues unique to this medium. Seven additional topics are targeted for development including osteoporosis, cardiovascular disease, depression, breast cancer, alcohol abuse, domestic violence and smoking cessation.

◆ University of Pennsylvania CoE

The University of Pennsylvania CoE conducted focus groups in an effort to establish a community outreach program that

overcame current barriers to health care and optimized the use of visually and linguistically accessible information pathways for Deaf women to empower them to become informed and effective consumers and self-advocates of health care services. Specific program goals included are:

- To provide advocacy, training and technical assistance to health care systems, managed care organizations, health care providers and institutions in making their services accessible to deaf women; and
- To provide deaf accessibility training and technical assistance to current providers of women's health information campaigns and health hotlines.

◆ University of Puerto Rico CoE

Starting in their first year, Integration Seminar Course exposes students to the discussion of cases targeting the development of skills in women's health and female patients management to be applied in all four years of the medical curriculum especially during the 3rd year. During the past year, under the leadership of the CoE Educational Co-Director and Course director, new cases for 1st and 2nd year students were developed to incorporate diverse issues related to women and their health. Cases included topics on: breast cancer, domestic violence, adolescent pregnancy and the female geriatric patient. The 2nd year Integration Seminar case revision committee revised three cases—alcohol consumption during pregnancy, fractures in female aged women, and lupus in an adolescent girl—to incorporate new women's health issues, particularly issues on health prevention and promotion. The CoE Associate Director served on that committee.

The University of Puerto Rico School of Medicine, the Bronx-Lebanon Hospital Center and the CoE jointly sponsored a Conference on Puerto Rican Women's Health in February 2001. Speakers included faculty members from the University of Puerto Rico and from Bronx-Lebanon Hospital and Albert Einstein School of Medicine. Topics covered included: Cardiovascular Disease; Diabetes; Breast cancer; HIV/AIDS; Menopause and Women's Health; Early Sterilization and Frequent Contraceptive Use and its influence on Puerto Rican Women; and Women's access to Health Care in Puerto Rico and in the Bronx. The activity is part of an agreement between the School of Medicine and Bronx-Lebanon University Hospital. This was the tenth conference under the School of Medicine and Bronx-Lebanon University Hospital agreement and the first to be dedicated to women's health. The conference program will be offered in New York in the fall 2001.

In March 2001, in commemoration of Women's Week and the inauguration of the new facilities of the Center of Maternal and Infant Studies (CEMI), the CoE co-sponsored the forum: "And, if it happened to me...the management of a diagnosis," The forum was held on March 9, at the school of Nursing Auditorium and was attended by 48 health care professionals. Panelists in the activity included: Dr. Carmen Zorrilla (HIV/AIDS Diagnosis), Dr. Edna Mora (Handling a Breast Cancer Diagnosis), Dr. Lily Santiago (Process of Disclosure of the Diagnosis to Others), Dr. Iris Zavala (Experience as a Cancer Patient) and Ms. Elizabeth Navedo (The Perspective of an HIV/AIDS Patient). Dr. Delia Camacho presented the introduction to the activity focusing on the classification of women as it relates to their reaction and participation when facing a life-threatening diagnosis.

The annual medical symposium: New Perspectives on the Care of Women's Health for Primary Care Physicians, is held every March at the Ritz Carlton Hotel. Sponsored by the CoE in collaboration with the UPR OB-GYN Department, with the educational sponsorship of a pharmaceutical company, it is now in its six year. Total attendance of the 2001 symposium was 700 physicians. The program included the following topics:

- The aging process: what can we prevent?
- Cardiovascular disease and estrogen
- Hormone replacement therapy and cancer in perspective
- Hormone Replacement therapy in patients with chronic diseases
- Hormone replacement therapy: Where are we going?
- Management of abnormal bleeding during perimenopause and menopause.

◆ Tulane/Xavier Universities CoE

The third year of medical school curriculum includes specific topics on women's health in the primary care rotations as well as the traditional obstetrics and gynecology rotations. Core lecture topics include Cardiovascular Disease in Special Populations and Health Promotion and Disease Prevention.

The Hutchinson Clinic ambulatory care rotation includes attendance in the primary care and specialty clinics. During the women's health clinic, the rotation integrates the spectrum of women's health with primary care. Clinical topics include bone health and osteoporosis, breast health, health promotion and disease prevention. An interdisciplinary approach is emphasized

and the concepts of case management are emphasized for statewide initiatives for Diabetes Mellitus, Asthma and Congestive Heart Failure.

The CoE co-hosted with the Xavier College of Pharmacy a continuing education forum entitled “Women’s Health Issues: Cardiovascular Disease/Risk Reduction.” Program objectives included to:

- Identify gender difference in risk factors for cardiovascular disease;
- Identify the indications, benefits, side effects, and contraindications of Hormone Replacement Therapy;
- Describe the influence of gender on antihypertensive drug use;
- Identify gender differences in symptomatology, diagnosis and treatment of coronary heart disease in women;
- Describe the influence of gender on the development of and treatment of Impaired Glucose Tolerance and Type 2 Diabetes.

As part of the commitment to lifelong learning in the medical profession, the CoE has developed a Women’s Health Lecture Series for physicians and other health care providers in the community. Topics for the lecture series include disease processes that are exclusively found in women, that disproportionately affect women, or that have significantly higher morbidity and/or mortality when compared to men. Topic areas include cardiovascular disease in women, osteoporosis, asthma, and gastroesophageal reflux disease.

The CoE has developed an osteoporosis lecture series. Faculty members present information on osteoporosis for each session, followed by participant case studies and group discussions.

The CoE collaborates on Women Wellness Wednesdays, a work site program which brings comprehensive health and wellness education to staff, addressing the physical, social, emotional and spiritual needs of women. Topic areas include cancer and cardiovascular disease.

◆ University of Illinois at Chicago CoE

The Center for Research on Women and Gender received funds from the Office of Women's Health, Illinois Department of Public Health, in October, 1998, to support a series of multidisciplinary continuing medical education programs in women's health for primary care physicians during 1999. The series was entitled Women's Health Issues: A Multidisciplinary Approach. On the basis of a needs assessment conducted among family physicians, three topics were selected for the series: breast cancer, heart disease, and domestic violence. The planning committee was composed of UIC faculty members from Family Medicine, Medical Education, College of Pharmacy, the Center for Research on Women and Gender, and the Illinois Academy of Family Physicians. Organizations that provided support were: American Cancer Society; American College of Obstetricians and Gynecologists, Illinois Section; American College of Physicians; American Society of Internal Medicine, Northern Illinois Chapter; American Heart Association, Midwest Affiliate; American Medical Women's Association, Branch #2; Chicago Medical Society; Mayor's Office on Domestic Violence, Chicago; Society of General Internal Medicine, Midwest Chapter; and

Y-ME National Breast Cancer Organization. The educational programs of SAFE ILLINOIS and Multi-city Mammography Project also had materials available at the CME programs.

◆ University of Wisconsin CoE

The CoE received a contract from the Department of Health and Human Services for one more year to participate in a broad health professional education effort around the ongoing health issues for those exposed to DES, including the children who were exposed to the drug in utero and for the mothers themselves who were exposed. The initiative involves the School of Medicine, Family Medicine, Nursing and the Physician's Assistant Program.

Barbara Loevinger, MD, is a psychiatrist who holds a Women's Health Fellowship sponsored by the CoE. She has a particular interest in the connection between mind and body, especially in stress-related disorders in women. She is currently working with faculty at the University of Wisconsin Mind-Body Center, and is studying women with fibromyalgia and rheumatoid arthritis.

Leadership

◆ University of Wisconsin, Madison CoE

The National Institute on Aging sponsors a Postdoctoral Fellowship in Women's Health research which is aimed to support MD and PhD postdoctoral trainees in women's health research with a focus on post-menopausal women. A special emphasis has been placed on recruiting and training individuals from racial and ethnic minority groups currently underrepresented as investigators in setting the women's health research agenda. The fellow chosen works with a selected mentor in the traditional apprentice-training model, and also has a core

group of women faculty available for mentoring, role modeling, and career advice. She attends the monthly forums, colloquiums, and meetings with faculty and staff. Research areas for these fellows have included gender differences in obesity, a medical history of menopause in America, and health services research into long-term care, primarily a women's issue. The fellowship is available for three years to the individual. The PI for the grant is the CoE Center Director.

The CoE Center Director is the Fellowship Director for the VA Women's Health Fellowship, a two-year program, with an optional third year, giving clinical and research training to general practitioners and psychiatrists. There is an option for an MS in Population Health through this program. Fellows have done research in such diverse topics as long term care, depression, and fibromyalgia.

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